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TITLE: Prostate Cancer Genetics in African Americans

PRINCIPAL INVESTIGATOR: Henry T. Lynch, M.D.

CONTRACTING ORGANIZATION: Creighton University, Omaha, NE 68178

REPORT DATE: September 2012

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Fort Detrick, Maryland 21702-5012

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14. ABSTRACT [Approximately 200 word summary of the most significant finding during the research period] Our intent has been to identify African American males diagnosed with prostate cancer between the ages of 40 and 75 and registering them along with their at risk relatives into a program of cancer education, cancer screening, and early intervention to reduce disparities in prostate cancer incidence and mortality rates in the African American community in Nebraska and Mississippi. Family history of prostate and other cancers is being recorded with the purpose of identifying any hereditary prostate cancer syndrome. This will be possible through the recruitment of a total of 800 African Americans who have been diagnosed with prostate cancer, through recruitment activities and screenings in Omaha, Nebraska, and Jackson, Mississippi. The most significant work during the first year of this grant has involved (1) hiring and training of research personnel; (2) the establishment of a project-specific database; and (3) beginning recruitment of research participants. The first of these objectives has been accomplished, with continuing education of personnel. The second has been achieved, with the database itself constructed and a database manual under preparation. The third is ongoing in Omaha and Jackson through cooperation with local urologists and outreach to the African American communities.									
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Introduction

Our intent has been to identify African American males diagnosed with prostate cancer between the ages of 40 and 75 and to enter them along with their at risk relatives into a program of cancer education, cancer screening, and early intervention to reduce disparities in prostate cancer incidence and mortality rates in the African American community in Nebraska and Mississippi. Family history of prostate and other cancers is being recorded with the purpose of identifying any hereditary prostate cancer syndrome. In addition, social and behavioral determinants are collected and recorded during the interview process for the final analysis. This will be possible through the recruitment of a total of 800 African Americans who have been diagnosed with prostate cancer, through recruitment activities and screenings in Omaha, Nebraska, and Jackson, Mississippi.

Body

Task 1: Participant Identification and Access (Years 1 and 2)

At Creighton University, recruitment of subjects has been ongoing through cooperation with local urologists (see letter in appendix) as well as through promotion to the community by study personnel's appearance on two local television programs that target the African American community, Real Talk and Healthy Choices on Omaha CTI22; attendance at local health fair; publication of an article about the study in *Omaha Star* newspaper serving the Omaha African American community; an announcement of the study emailed to all online subscribers of the *Omaha World Herald* newspaper; an advertisement on the study emailed to all Creighton University physicians in their monthly School of Medicine newsletter; creation of a billboard to be displayed in a key location throughout September 2012; and compilation of lists of church leaders and secretaries and neighborhood watch leaders who will receive email or written study invitations to share with their communities (see appendix for material used for these recruitment efforts).

Seventy-five participants have been identified at Creighton who meet the eligibility criteria. Ten of these participants have been interviewed and data collected from the interviews has been entered into the study-specific database according to protocol. DNA has been collected and stored according to protocol for those eligible participants who have agreed. The remaining 65 participants have received a letter introducing the study and informing them that the project coordinator will be contacting them regarding participation.

At Jackson State, project year one was used to train personnel and prepare for substantive recruitment and data collection. A project research coordinator and two graduate assistant were hired. Research personnel visited Creighton University for training, as planned, and a visit by Creighton personnel to Jackson State is scheduled for September 24-25, 2012. Financial transactions were implemented for participant recruitment and data collection. There were preparations regarding participant incentives, participant recruitment, and data collection packages.

Although no interview or blood collection data have been entered into the database at Jackson State, data regarding the recruitment process have been collected with 54 individuals recruited and agreeing to participate; 28 of these have been communicated with and are in the process of receiving interview preparation packets. Currently, the project has reached a stage where a high yield of recruitment and high throughput of data and specimen collection can be implemented. Key materials are now in place for data and specimen collection from 138 participants who are ready to participate within the first quarter of year 2. The list of individuals with positive diagnoses of prostate cancer has been updated to 255. Urologists continue to inform patients of the study.

Task 2: Data Collection and Management (Years 1 through 2.5)

The study-specific database has been constructed, including onscreen instructions for its use (see appendix for representative screenshots). As stated above, data collection has begun at Creighton and is set to begin at Jackson State.

The database variables on social and behavioral determinants and risk exposure pathways suggested by the community partners were added to the database with appropriate quality controls incorporated into the program.

Work continues on the completion of the database manual.

Task 3. Prostate Cancer Prevention and Health Education and Referral (Years 1.5-3)

Screening interviews have begun, with participants positive for prostate cancer family history being identified and receiving appropriate education, genetic counseling, and/or referral. During each interview the research coordinator identifies at risk family members and encourages the participant to discuss their risk with them as well as our screening recommendations. The participant can also ask the family member to call the research coordinator directly to discuss their risk and the recommendations. The Jackson State University team developed and gave a presentation to a prostate cancer

support group at their meeting on July 19, 2011. This presentation has been shared with the Creighton University Community Engagement Team.

Challenges

Financial transaction for travel, acquisition of materials (stationery, supplies, participant gift card incentives), participant interviews, data and blood collection were a challenge due to delays.

Lessons learned in meeting challenges:

- That transactions, not direct research activities, were a source of delay in the commencement of research data collection;
- That set protocols for the financial interactions can help to overcome some challenges;
- That early preparation for recruitment can provide a buffer for continuous interviews for data collection and blood draw to meet data collection quota;
- That active physician involvement in recruitment activities is key to participant recruitment and provides very high yields in participant participation.

Key Research Accomplishments

- Recruitment and training of study personnel: research project coordinators at both sites as well as two graduate students at Jackson State University.
- Development of a study specific Access database with embedded quality control measures that is used at both research sites.
- A collaborative meeting between the two research groups completed in year one.
- Subject recruitment measurements implemented through television, newspaper, community events, prostate cancer support groups, billboards and emails to community and church leaders, local urologists and all active physicians in the area.
- Identification of 75 eligible participants wherein ten were interviewed at Creighton University. Their data has been entered into the database and DNA samples have been collected and stored on 3 participants who were eligible and volunteered to donate the sample. Two-hundred and fifty-five subjects have been identified at Jackson State University wherein 138 participants are ready to participate within the first quarter of year 2.
- Prostate cancer prevention and health education occurring at each interview as well as during each television broadcast regarding the study. Jackson State University also provided an educational presentation to a prostate cancer support group.

Reportable Outcomes

- An education presentation was done on July 19, 2011 by the Jackson State University team for a prostate cancer support group.
- Three blood samples have been obtained and stored for future genetic studies on eligible participants.
- A study specific Access database has been developed.

Conclusion

To date, we have identified 330 eligible participants for the study through local urologists. Ten individuals have been interviewed with data entered and blood samples stored for the study. Multiple recruitment measures have been implemented to increase recruitment numbers and raise interest in the communities. Current recruitment measures will continue while additional avenues of recruitment will be explored with Creighton's Public Relations department.

Ascertainment of eligible participants will be of utmost priority at both sites during quarters one and two of Year 2. Of the ten subjects interviewed, six had a significant family history defined as at least one other relative with prostate cancer. As an exemplar, one family has six cases of prostate cancer: the proband, two of his brothers, his father and two maternal uncles. Please refer to the Family A pedigree in the Appendix. Educational and early screening measures were discussed with the participant during the interview. The proband's son as well as his nephews were encouraged to begin their prostate cancer screening at age 45 rather than waiting until age 50. The findings of this study will have a significant impact on high risk individuals in families such as this one as well as the knowledge of familial prostate cancer and the role of early detection and prevention.

In 2010 Whitman et al. and Hooker et al. identified at risk loci specific to prostate cancer in African Americans. These loci may be targets to test in the future on the stored DNA samples from participants in families with familial prostate cancer from this study.

References

Whitman EJ, Pomerantz M, Chen Y, Chamberlin MM, Furusato B, Gao C, Ali A, Ravindranath L, Dobi A, Sestrehenn IA, McLeod DG, Srivastava S, Freedman M, Petrovics G. Prostate cancer risk allele specific for African descent associates with pathologic stage at prostatectomy. *Cancer Epidemiol Biomarkers Prev* 2010;19:1-8.

Hooker S, Hernandez W, Chen H, Robbins C, Torres JB, Ahaghotu C, Carpten J, Kittles RA. Replication of prostate cancer risk loci on 8q24, 11q13, 17q12, 19q33, and Xp11 in African Americans. *Prostate* 2010;70:270-275.

Appendices

Please see attached.

mailed - 6.26.12

Department of Preventive Medicine
and Public Health

COPY

Creighton
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Hereditary Cancer Center

June 14, 2012

Bruce Lundak, M.D.
President, Urological Society of Nebraska
Bergan Mercy Professional Center
7710 Mercy Road, Suite 406
Omaha, Nebraska 68124-2346

Dear Dr. Lundak:

Creighton University's School of Medicine (Department of Preventive Medicine and Public Health and the Center for Promoting Health & Health Equality), in collaboration with Jackson State University, Jackson, Mississippi, has been awarded a grant by the Department of Defense to study the genetics of prostate cancer (PC) among African Americans (AAs).

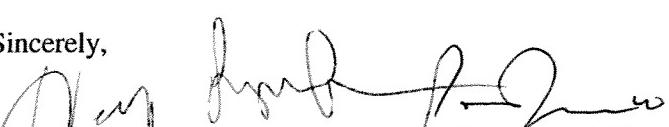
Our primary objective is to identify familial and/or hereditary patterns of PC's occurrence in AAs. Attention will be given to cancer of all anatomic sites within the family of each index case, as ongoing research at Creighton has shown that virtually all forms of hereditary cancer involve multiple anatomic sites wherein the pattern of these cancers' occurrence can be used beneficially for hereditary cancer syndrome diagnosis leading to targeted screening regimens.

We believe that the familial/hereditary predisposition of PC among AAs may differ strikingly from Caucasians given the fact that AAs have a more than two-fold increased lifetime risk for PC and their response to conventional management is also less effective. In addition to garnering a better understanding of PC's etiology among AAs, we believe that this knowledge will prove useful for screening and management.

We would greatly appreciate your help in this project. Please let us know if we can be of help in getting the word out to the members of the Urological Society of Nebraska, as we need to recruit 300 AAs with PC for the study. We would welcome any opportunity available for us to present the study to the members at a society meeting.

Attached is a summary of study needs as a document that may be distributed for patient referral.

Sincerely,


Henry T. Lynch, M.D.
Principle Investigator
Professor of Medicine &
Chairman of Dept. of
Preventive Medicine &
Public Health


Paulos Yohannes, M.D.
Clinical Professor of Surgery
CEO Urorobotics, PC


Sade Kosoko-Lasaki, M.D.
Co-Investigator
Assoc. VP Health Science
Professor of Surgery &
Preventive Medicine & Public
Health

Attachment

cc: Euclid De Souza, M.D.

Summary of Need for Creighton University Prostate Cancer Study

Purpose: To describe the patterns of cancer occurrences and epidemiologic factors in African-American families that have demonstrated an increased amount of prostate cancer.

- Subject criteria: African-American male diagnosed with prostate cancer between the ages of 40-75 years.
- Recruitment need: 300 subjects within the first two years of the grant (August 2011 – August 2013).
- Participation includes:
 - Completion of a family history questionnaire;
 - Completion of an epidemiologic questionnaire;
 - For those who have another family member with prostate cancer, drawing of blood and storage of a blood-derived DNA sample.
- All data and DNA samples will be stored in Creighton University's Hereditary Cancer Center secure registry and bio-repository.
- None of the candidate subjects will be contacted regarding the study without their or their physician's permission.
- Once a candidate subject has agreed to be contacted for the study, his name and telephone number can be provided to our project coordinator, Carrie Snyder, MSN, RN, APNG. Ms. Snyder will then contact the individual, explain the study, and obtain informed consent for those who agree to participate. Contact information is as follows:

Carrie Snyder, MSN, RN, APNG

Telephone: 402-280-2634

Fax: 402-280-1734

Email: csnyder@creighton.edu

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LTH & WELLNESS/NATIONAL NEWS

July 27, 2012

African American Men and Prostate Cancer

African-American men are twice as likely to get prostate cancer - and twice as likely to die from it - as are Caucasians. African ancestry (having ancestors from Africa south of the Sahara Desert) by itself puts black men at high risk for getting prostate cancer. Because it's not known why this is so, Creighton University research may help to find a piece of the puzzle.

Creighton University researchers would like to talk to 300 African American men from the Omaha area who were told by their doctors that they had prostate cancer when they were between the ages of 40 and 75. They want to talk to men

who have relatives with prostate cancer as well as those who don't.

Why do the researchers want to involve men with prostate cancer running in their families and those who don't? Because they want to compare the two groups and see if there is a difference between prostate cancer that runs in families and prostate cancer that doesn't. Having more than one close relative who has had prostate cancer also puts a man at higher risk, and the more relatives who have had this disease the higher the risk. Men who have a father or brother with prostate cancer are twice as likely to develop it as men with no relatives affected.

Besides the questions the research is trying to

answer, the study is important to the community because men with African ancestry and those with prostate cancer running in their families need to know about their high risk for prostate cancer and should be screened for it more often and earlier than other men. Screening can detect the cancer while it is still early enough to cure. In addition, for men in the study who already have prostate cancer, the information they will receive through the study can help them, their close relatives, the community and their doctors decide on the best plan for screening.

Each man participating in the study will be interviewed about personal and family health history and other known risks related to prostate cancer. Family histories will be collected,

research participants will learn the meaning of their own family histories and will be given information about screening and other research studies.

The funds for this study have been awarded by the Department of Defense. The same research is being done in partnership with researchers at Jackson State University in Jackson, Mississippi, a Historically Black University. Most of the African Americans in Omaha have family in Mississippi.

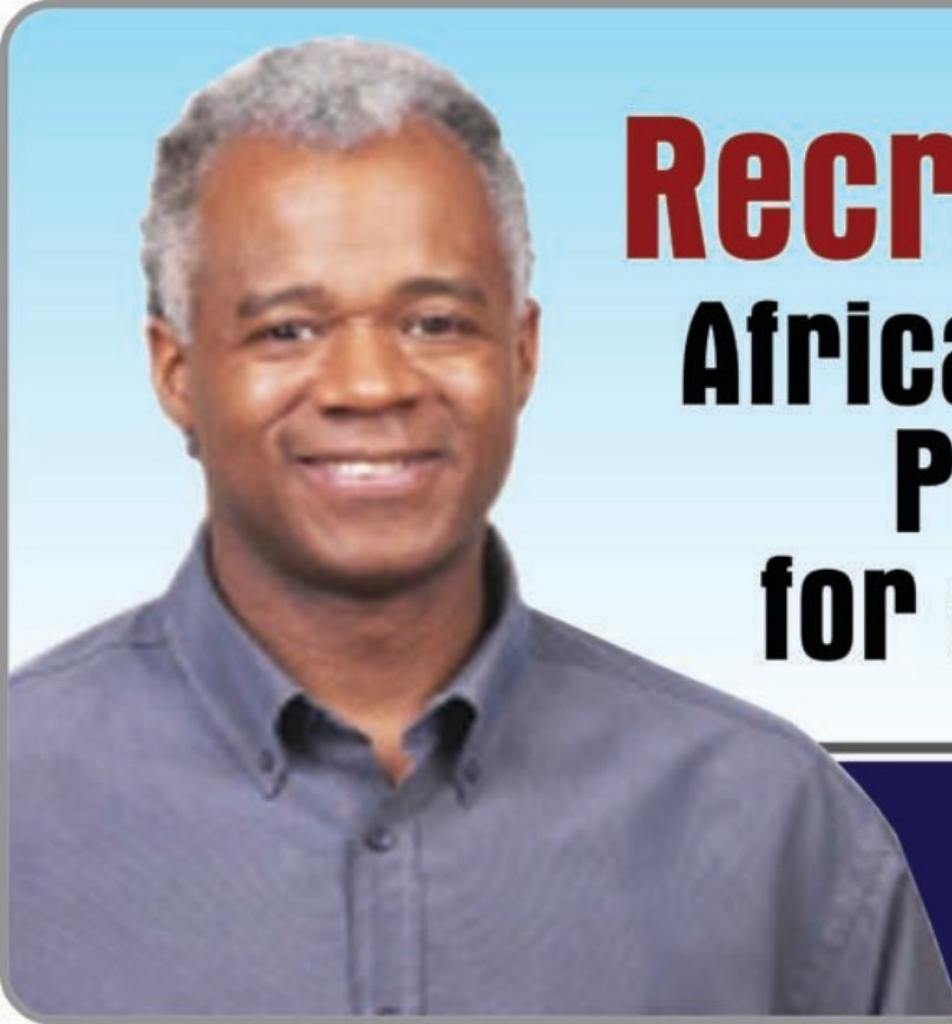
The study has been approved by the Creighton

and Jackson State's Institutional Review Boards (IRB) and this ensures that the program is safe, sound and beneficial. Everything about the study will be strictly confidential, and personal information will be kept securely private. Anyone may decline participation in this study at any time with no penalty, even after the study has started.

Any African-American man who has had prostate cancer between the ages of 40 and 75 is invited to contact Creighton's Department of Preventive Medicine and Public Health to find out how to become part of the study. Please phone Carrie Snyder at 402.280.2942 or email her at cnyder@creighton.edu. If you'd like to speak with a study doctor, she can put you in touch with them.

Creighton researchers plan to share the results of the research with members of the African American community after the study is over. We greatly appreciate those who can help in this research study on prostate cancer in African-American men.

Henry T. Lynch, M.D.
Paulos Yohannes, M.D.
Shade Kosoko-Lasaki, M.D.
Carrie Snyder, M.S.N., R.N., A.P.N.G.



Recruiting: African American Men with Prostate Cancer for a genetic study.

Creighton
UNIVERSITY

Call... 402.280.2942

for more information.

FOR MORE INFORMATION:
N. Kathryn Clark (402) 280-2864
KathrynClark@creighton.edu

Creighton Study to Look at Hereditary Prostate Cancer in African Americans

For Immediate Release: Aug. 18, 2011

OMAHA, Neb. – Creighton University's Hereditary Cancer Center, has received a three-year, \$731,278 grant from the U.S. Department of Defense to study the role heredity plays in prostate cancer among African Americans.

"Prostate cancer is the leading cause of cancer death among men in the United States,. African American men have two times the occurrence of prostate cancer as do Caucasian men and suffer a significantly higher mortality as well," said Henry Lynch, M.D., principal investigator and Creighton Hereditary Cancer Center director.

While it's estimated that about 10 percent of all prostate cancers have a hereditary link, the problem has been understudied in African Americans. With few exceptions, relatively little is known about the role genetics play in this population, noted Lynch, the Charles F. and Mary C. Heider Endowed Chair in Cancer Research.

The study will focus on identifying the hereditary factors of the disease that are specific to African Americans. The goal is to develop early and intensive screening and prevention management strategies that will decrease African Americans' incidence of as well as death rate from hereditary prostate cancer, he said.

Jackson State University in Mississippi is collaborating in the study. The goal is to involve 300 African American prostate cancer patients from the Omaha area and about 500 from Jackson, Miss., in the effort.

The research team includes members of Creighton's Hereditary Cancer Center; Olúgbémiga Ekúndayò, M.D., associate professor of epidemiology at Jackson State University,

and his staff; Sade Kosoko-Lasaki, M. D., associate vice president of Health Sciences Multicultural and Community Affairs and co-director of Creighton's Center for Promoting Health and Health Equality; and Paulos Yohannes, M. D., Creighton assistant clinical professor of surgery.

If you are an African American who has been diagnosed with prostate cancer, and are interested in participating in the study, contact Carrie Snyder, cancer genetics nurse specialist, at 402.280.2634 or e-mail csnyder@creighton.edu and include "prostate cancer study" in the subject line.

To learn more about the work of Creighton's Hereditary Cancer Center, visit <http://medicine.creighton.edu/HCC>.

###

About Creighton University: Creighton University, a Catholic, Jesuit institution located in Omaha, Neb., enrolls more than 4,100 undergraduate and 3,200 professional school and graduate students. Nationally recognized for providing a balanced educational experience, the University offers a rigorous academic agenda with a broad range of disciplines, providing undergraduate, graduate and professional degree programs that emphasize educating the whole person: academically, socially and spiritually. Creighton has been a top-ranked Midwestern university in the college edition of *U.S. News & World Report* magazine for more than 20 years. For more information, visit our website at: www.creighton.edu.



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Creighton gets grant to study heredity-cancer link

Published 04:40 a.m., Monday, August 29, 2011

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OMAHA, Neb. (AP) — Researchers at Creighton University have gotten a federal grant to study how heredity affects prostate cancer in black men.

Creighton Hereditary Cancer Center director Henry Lynch says prostate cancer is the leading cause of cancer deaths among American men and is more prevalent among black men than whites. Hereditary is believed to be a link in 10 percent of cases.

Creighton is partnering with Jackson State University in Mississippi on the study. They're seeking 300 black men diagnosed with prostate cancer from eastern Nebraska and about 500 from Jackson, Miss. For details, visit <http://bit.ly/dn25uy>.

The grant money comes from the U.S. Department of Defense.

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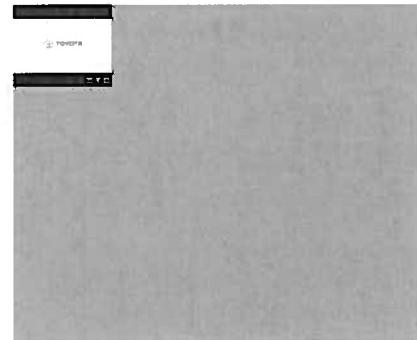
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Published Tuesday August 23, 2011

Heredity, prostate cancer to be studied

By Bob Glissmann
WORLD HERALD STAFF WRITER

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It's estimated that about 10 percent of all prostate cancers have a hereditary link. But relatively little is known about the role heredity plays in the incidence of prostate cancer among blacks.

To study that link, Creighton University's Hereditary Cancer Center has received a three-year, \$731,278 grant from the U.S. Department of Defense.

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"African-American men have two times the occurrence of prostate cancer as do Caucasian men and suffer a significantly higher mortality as well," said Dr. Henry Lynch, principal investigator and the director of the Creighton center.

The study will focus on identifying the hereditary factors of the disease that are specific to African-Americans. The goal is to develop early and intensive screening and prevention-management strategies, Lynch said.

Jackson State University in Mississippi is collaborating in the study. The goal is to involve 300 African-American prostate cancer patients from the Omaha area and about 500 from Jackson, Miss.

If you are a black man who has been diagnosed with prostate cancer and are interested in participating in the study, contact Carrie Snyder at 402-280-2634 or email csnyder@creighton.edu and include "prostate cancer study" in the subject line.

Contact the writer: 402-444-1109, bob.glissmann@owh.com

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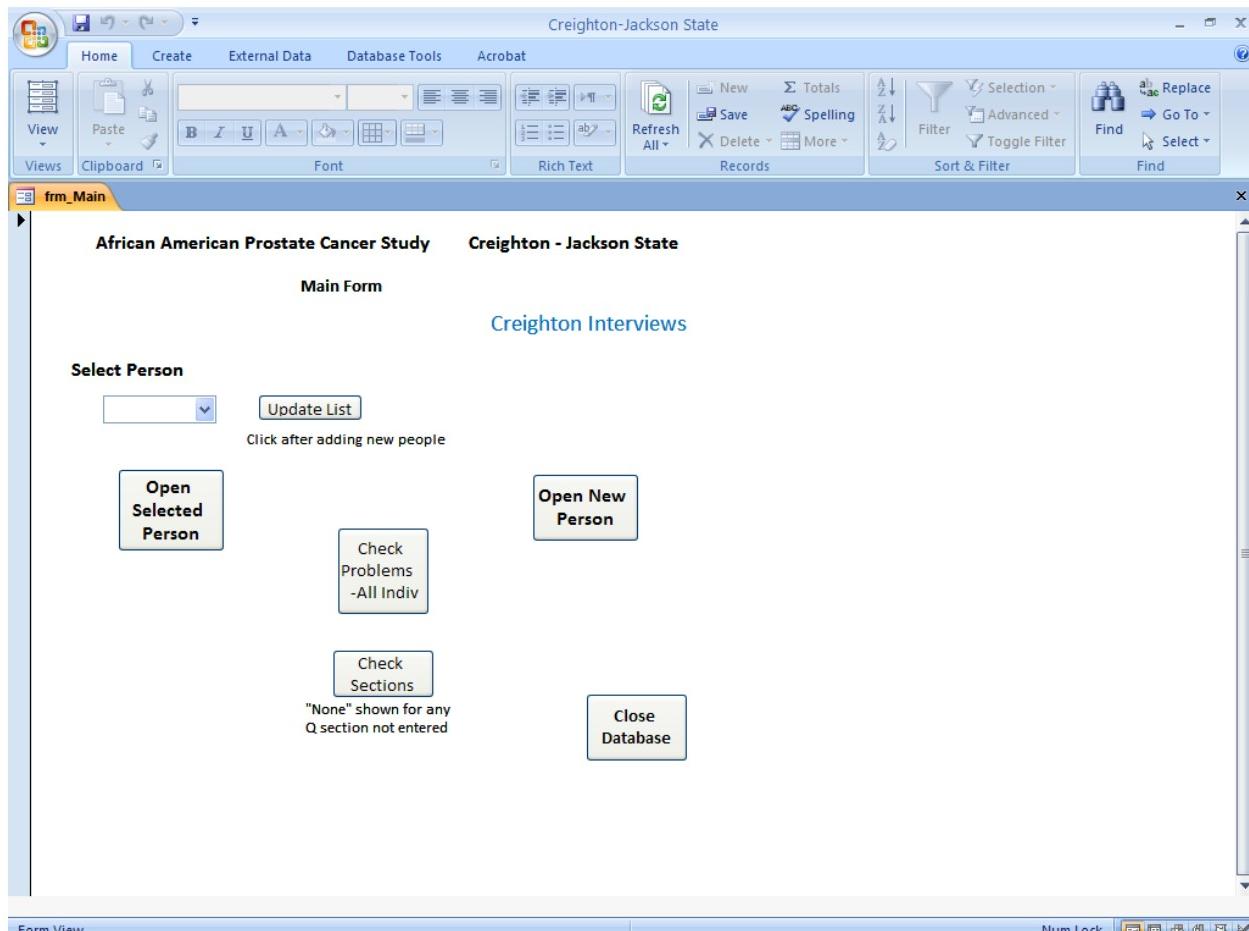
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Jackson State Database



Creighton-Jackson State

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African American Prostate Cancer Study Creighton - Jackson State ID: 27

Questionnaire
 Date Time Start Time End Interviewer
 Title: Mr Mrs Ms Miss Other
 Name: Last First Mid Maid
 Street: City: St Zip:
 Phone: Home Work email:

Demographics

Date Birth (mm/dd/yyyy) Multiple Birth No Yes Birth Order Twin
 Gender Female Male
 Marital Status: Never Married Single Widow(er) Married Divorced
 Separated Co-habiting

Race: -Identify self as African American Yes No Multiple Decline to Answer
 Specify Race Groups:

Insurance -Have: health care insurance life insurance
 private/group Medicare/Medicaid

Adopted No Yes Name1 Relation1
 Name2 Relation2

Form View Num Lock Filtered

Creighton-Jackson State

frm_Main frm_Demog

Street: City: St: Zip:
 Phone: Home Work email:

Demographics

Date Birth (mm/dd/yyyy) Multiple Birth No Yes Birth Order Twin
 Gender Female Male
 Marital Status: Never Married Single Widow(er) Married Divorced
 Separated Co-habiting

Race: -Identify self as African American Yes No Multiple Decline to Answer
 Specify Race Groups:

Insurance -Have: health care insurance life insurance
 private/group Medicare/Medicaid

Adopted No Yes Name1 Relation1
 Name2 Relation2
 Name3 Relation3

Other Sections

Medical History Social History Psychosocial History Environmental History Check Problems Close Form

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Creighton-Jackson State

Medical History

Fam-Ind 1111 - 1 ID: 27

Height Current Weight Wt age 18 Wt age 30 Wt age 40
 Heaviest Wt at age round wt to whole pound

Take aspirin No Yes for pain heart/stroke prev How long:
 Other

Cancer History

Ever diagnosed with cancer? No Yes
 Date Site How detected:
 checkup symptoms type:
 checkup symptoms type:

Diagnosed with hereditary disorder? No Yes
 Specify:

Prostate Cancer History

digital rectal exam? No Yes Age of 1st
 Regular No Yes Often:
 blood test? No Yes Age of 1st
 Regular No Yes Often:
 enlarged prostate No Yes Date:
 Surgery No Yes Date:
 positive PSA No Yes Date:

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Creighton-Jackson State

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digital rectal exam? No Yes Age of 1st
 Regular No Yes Often:
 blood test? No Yes Age of 1st
 Regular No Yes Often:
 enlarged prostate No Yes Date:
 Surgery No Yes Date:
 positive PSA No Yes Date:

Other Medical Conditions

anemia (Chronic) sleep problems Chron's disease alcoholism
 diabetes heartburn ulcerative colitis psychiatric problem
 hypertension glaucoma obesity Other

Physical Activity

Childhood	<input type="checkbox"/> None	<input type="checkbox"/> VLite	<input type="checkbox"/> Light	<input type="checkbox"/> Mod	<input type="checkbox"/> SwHard	<input type="checkbox"/> Hard	<input type="checkbox"/> Very hard
High school	<input type="checkbox"/> None	<input type="checkbox"/> VLite	<input type="checkbox"/> Light	<input type="checkbox"/> Mod	<input type="checkbox"/> SwHard	<input type="checkbox"/> Hard	<input type="checkbox"/> Very hard
19 - 29	<input type="checkbox"/> None	<input type="checkbox"/> VLite	<input type="checkbox"/> Light	<input type="checkbox"/> Mod	<input type="checkbox"/> SwHard	<input type="checkbox"/> Hard	<input type="checkbox"/> Very hard
30 - 39	<input type="checkbox"/> None	<input type="checkbox"/> VLite	<input type="checkbox"/> Light	<input type="checkbox"/> Mod	<input type="checkbox"/> SwHard	<input type="checkbox"/> Hard	<input type="checkbox"/> Very hard
40 - 49	<input type="checkbox"/> None	<input type="checkbox"/> VLite	<input type="checkbox"/> Light	<input type="checkbox"/> Mod	<input type="checkbox"/> SwHard	<input type="checkbox"/> Hard	<input type="checkbox"/> Very hard
50 - 59	<input type="checkbox"/> None	<input type="checkbox"/> VLite	<input type="checkbox"/> Light	<input type="checkbox"/> Mod	<input type="checkbox"/> SwHard	<input type="checkbox"/> Hard	<input type="checkbox"/> Very hard
60 - 69	<input type="checkbox"/> None	<input type="checkbox"/> VLite	<input type="checkbox"/> Light	<input type="checkbox"/> Mod	<input type="checkbox"/> SwHard	<input type="checkbox"/> Hard	<input type="checkbox"/> Very hard
70 - 79	<input type="checkbox"/> None	<input type="checkbox"/> VLite	<input type="checkbox"/> Light	<input type="checkbox"/> Mod	<input type="checkbox"/> SwHard	<input type="checkbox"/> Hard	<input type="checkbox"/> Very hard

Close Form

How frequently exercise:

Work involves physical activity None Little Some Most Nearly All All

Daily routine involves physical activity None Little Some Most Nearly All All

Form View Num Lock Filtered

Creighton-Jackson State

Social History

Fam-Ind 1111 - 1 ID: 27

Education

- Elementary Middle High School GED
- Tech/Vocation certificate College/Postgraduate

Income and Employment

Income during	Childhood	Now	Current Employment
None	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Full time
Up to 4,999	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Part time
5,000-14,999	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Unemployed
15,000-29,999	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Retired
30,000-49,000	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Self-employed
50,000-59,000	<input type="checkbox"/>	<input type="checkbox"/>	
60,000-69,000	<input type="checkbox"/>	<input type="checkbox"/>	
70,000-79,000	<input type="checkbox"/>	<input type="checkbox"/>	
80,000-above	<input type="checkbox"/>	<input type="checkbox"/>	

Gov't assistance Yes No Decline to answer Hours worked/day:

Housing

Type: Own Rent Home Apt Condo Mobile Live: Alone Family Friends Num

Neighborhood

is safe	<input type="checkbox"/> Yes	<input type="checkbox"/> No	Walk or run	<input type="checkbox"/> weekly
know parks	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> daily	<input type="checkbox"/> 2/month
use parks	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> 4/week	<input type="checkbox"/> less 2/mo
know recreation	<input type="checkbox"/> Yes	<input type="checkbox"/> No		

Form View Num Lock Filtered

Creighton-Jackson State

Social History

Fam-Ind 1111 - 1 ID: 27

Gov't assistance Yes No Decline to answer Hours worked/day:

Housing

Type: Own Rent Home Apt Condo Mobile Live: Alone Family Friends Num

Neighborhood

is safe	<input type="checkbox"/> Yes	<input type="checkbox"/> No	Walk or run	<input type="checkbox"/> weekly
know parks	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> daily	<input type="checkbox"/> 2/month
use parks	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> 4/week	<input type="checkbox"/> less 2/mo
know recreation	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> 2/ week	<input type="checkbox"/> never
can walk	<input type="checkbox"/> Yes	<input type="checkbox"/> No		

Rating: Most people can be trusted Have to be alert or they take advantage
 Most people willing to help People do not trust in money matters

Transportation

Have a vehicle: Yes No Travel by: Taxi Bus Friend/neighbor Family member
 Miles travel for food: Miles travel to see doctor:
 Go out mostly with: Family Friends Neighbors Co-workers Self Other

Close Form

Form View Num Lock Filtered

Creighton-Jackson State

frm_Main frm_Demog frm_PsychoSoc

Psychosocial History

Fam-Ind 1111 - 1 ID: 27

Childhood

Grew up with: Mother Father GrandParent Aunt/Uncle Cousin Adopted
 Siblings Other

Lived in: Big city Small city Small town Suburb Rural Farm

Mississippi Participants Delta Southern MS Northeast MS Coastal MS Northwest MS
 Central MS Southwest Other

Nebraska Participants North Omaha South Omaha Midtown West Omaha
 Other

Communication

Click to Enter or Review Places Lived

Attended Church: Regularly Occasionally Holidays Never

Anyone discuss health with No Yes

Discuss with: Father Siblings Friend Doctor
 Mother Children Cousin Counselor
 Wife Uncle Co-Worker Other
 Husband Aunt Pastor

Trust

To what extend do you trust:

Extremely	Quite a bit	Moderately	Little bit	None
-----------	-------------	------------	------------	------

Record: 1 of 1 Filtered Search Form View Num Lock Filtered

Creighton-Jackson State

frm_Main frm_Demog frm_PsychoSoc

Attended Church: Regularly Occasionally Holidays Never

Communication

Anyone discuss health with No Yes

Discuss with: Father Siblings Friend Doctor
 Mother Children Cousin Counselor
 Wife Uncle Co-Worker Other
 Husband Aunt Pastor

Trust

To what extend do you trust:

Extremely	Quite a bit	Moderately	Little bit	None
-----------	-------------	------------	------------	------

your race/ethnic group
other race/ethnic group
local govt officials
state govt officials
federal govt officials
police
health care provider

Attitudes toward Self

Agreement with statements:

Embarassed to see doctor Care and respect from health care provider

How often feel:

	Always	Often	Rarely	Never
Stressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Misunderstood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not listened to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Close Form

Record: 1 of 1 Filtered Search Form View Num Lock Filtered

Creighton-Jackson State

Home Create External Data Database Tools Acrobat

Views Clipboard Font Rich Text Refresh All New Totals Spelling Filter Selection Advanced More Sort & Filter Toggle Filter Find Replace Go To Select Find

frm_Main frm_Demog frm_Environ

Environmental History Fam-Ind 1111 - 1 ID: 27

Used tobacco No
 Yes cigarettes packs/day:
 Pipe cigars
 chewing tobacco snuff
age start age stop years smoked

Lived with a smoker No Yes #years:

Ever consumed alcohol No
 Yes Alcoholic drinks per week 0-3 4-9 10+
Types:
Age Start:
Age Stop:
Years:

Close Form

Form View Num Lock Filtered

This screenshot shows a Microsoft Access form titled "Environmental History" for individual ID 27. The form includes sections for tobacco use, living with a smoker, alcohol consumption, and a types field. It features a ribbon bar with various tools and a status bar at the bottom.

Tobacco Use: Used tobacco? (No)
Yes cigarettes packs/day:
 Pipe cigars
 chewing tobacco snuff
age start age stop years smoked

Living with a Smoker: Lived with a smoker? (No) Yes #years:

Alcohol Consumption: Ever consumed alcohol? (No)
Yes Alcoholic drinks per week: 0-3 4-9 10+
Types:
Age Start:
Age Stop:
Years:

Buttons: Close Form

African American Prostate Cancer Study
Creighton - Jackson State
Questionnaire Database Notes

Overview

Two identical Microsoft Access databases are used to record questionnaire responses. One, located in Omaha and named Prostate_CU, is used for Creighton managed interviews. The other, located in Jackson and named Prostate_JSU, is used for Jackson State managed interviews. They are designed to run with the 2007 version of MS Access.

Each database has a main screen plus a screen for each section of the questionnaire. The section screens (Demographics, Medical, Social, etc.) roughly mimic the layout of the questionnaire. Each input item has a label that is abbreviated from the question. Two items, employment history and places lived, have a button that opens a screen where multiple responses can be listed. The demographics screen also serves as a control for the person since it contains buttons that open each of the other screens for that individual. The database contains edit checks on the input data. There are buttons that list problems, and message boxes that alert to a probable error.

Each person is identified in the database with a Family – Individual number (Fam-Indiv). When a person is first input, the database assigns an ID number to the person that is used by the database to coordinate the records for that person. Although the ID is shown on the screens, it can be ignored by someone doing data input. It is assumed there will be only one questionnaire in the database for each individual.

Data Input and Navigation

When the database is opened, the Main Form automatically appears. This form is used for control purposes. There are 2 ways to open the data for a person.

- 1) Use the Open Selected Person button. This goes directly to the data for the individual highlighted in the Select Person drop down box at the upper left of the screen. Click on the down arrow to see a list of Fam-Indiv numbers, then click on the desired person. After selecting the person, click the Open Selected Person button to go to the Demographics screen. To have a complete list in the drop down box, there is an Update List button that must be clicked after new individuals have been added. This method is used to return to a previously entered person for edit or review.
- 2) Use the Open New Person button. This will open a blank Demographics screen. Start by entering the Fam-Indiv numbers, then proceed with the remainder of the data.

The Demographics screen contains the personal and demographic inputs for the individual. It also contains buttons to open the four history sections of the questionnaire. Always use these buttons to open the history forms.

Always close each history form before going to another form. This is important because forms left open can cause data to be linked to the wrong person! Use the Close Form button on each form, because some include edit checks. When a history form is closed, the process returns to the Demographics form, and another history form can be selected.

The Social History form has a button to open the Employment History form. The Psychosocial History form has a button to open the Places Lived form. Multiple items can be entered on these forms. Always close these forms, and use the Close Form button to do so.

Much of the input is to check boxes. Use the mouse to check the box corresponding to the answer checked on the questionnaire. Some of the forms have date inputs, and a small calendar appears to the right when the input is selected. The format is mm/dd/yyyy, and it may be easier to type the date than to scroll the calendar. Exceptions are the employment history and places lived, which are free-form entry text boxes. The tab order on the forms often skips the check boxes. When using the tab key, it is possible to tab past the current form which opens a new form. This should be avoided, and a red warning to close the form will appear below the Close Form button.

The Demographics screen also has a Check Problems button which runs a query listing any input problems found for the person. The query is closed by clicking the x to the right of the qProblems tab. Use the Close Form button on the Demographics form to return to the main form.

The Main Form has a Check Problems –All Indiv button which runs a query listing input problems found by the edit checks for all persons in the database. More on these edits in the Edit Checks section below. The query is closed by

clicking the x to the right of the qProblems tab. The Check Sections button runs a query that reports, for any person entered in the Demographics section, any history sections which have no data entered. In this case "None" will appear under the section name. The query is closed by clicking the x to the right of the qCheckSections tab. The form also has a Close Database button, used to exit the database.

Edit Checks

Many of the questions have edit checks. These cause message boxes to appear stating the problem. Clicking OK closes the message, but the input person needs to fix the problem or it will remain in the saved data. A common check is conflicting answers, e.g. both Yes and No, Male and Female, Twin and Triplet, Light and Hard, None and All. Checks where only one should be selected are included, e.g. Title, Marital Status, Income level, Housing Type. Ratings must be 1 through 5. Questions with additional information if Yes may show a message if No is checked and the Yes information is entered. If the weight at any age is more than Heaviest Wt, a message will appear.

These edits also appear on the lists from the Check Problems buttons if not resolved before the button is clicked. Additional checks on the lists are for questions that are not answered. The lists can be printed for follow-up.

Database Structure

Each form (except frm_Main) has a table to hold data for that form. The demographics table (tbl_Demogr) has field "ID" which is an autonumber, meaning the database automatically creates the ID when data is first entered for a person on the demographics form. All other tables contain the ID field, which is the link to the person's identity in the demographics table (including the Fam-Indiv number). Each table has its' own sysid field, which is an autonumber that provides a unique identifier for that record. Table ErrorList is a temporary table for holding the results from the Check Problems buttons, driven by VBA code in module ErrorFind. Each form has VBA code for navigation and error checking purposes, often using Click and AfterUpdate methods.

Creighton University School of Medicine
Department of Preventive Medicine and
Hereditary Cancer Center
2500 California Plaza
Omaha, Nebraska 68178

Jackson State University
School of Health Sciences
350 West Woodrow Wilson Drive
Jackson Medical Mall, Room 231
Jackson, Mississippi 39213

Date

Interviewer:

JSU#

Time Started:

CU#

SECTION 1: DEMOGRAPHICS and PERSONAL INFORMATION

D.1. Title Mr. Mrs. Ms. Miss Other

D.2. Name: _____

Last	First	Middle	Maiden
_____	_____	_____	_____
Street	City	State	Zip
_____	_____	_____	_____

D.3 Home/Cell Phone: _____

D.4. Work Phone:

D.5. E-mail Address:

1.3. Gender: Female Male

1.4. Marital Status: Never Married Single Widow(er) Married Divorced
 Separated Co-habiting

1.5. Race: Do you identify yourself as being African American?

Yes No Multiple Decline to Answer

Please specify all racial groups you identify with by blood

1.6. Do you have: health care insurance

private/group Medicare/Medicaid

1.7. life insurance?

1.7. Are you or other relatives adopted?

No Yes → Name: _____
Name:

Relationship: _____
Relationship:

SECTION 2: MEDICAL HISTORY

2.2 Cancer History

a. Have you ever been diagnosed with cancer?

No Yes → Please list date(s) of diagnosis, original site(s)/type(s) of cancer (such as colon cancer, leukemia, breast cancer), and how the cancer was detected.

Date	Site	How detected	
		during check-up	due to symptoms; type of symptoms (please write)

- b. Have you or one of your relatives been diagnosed with a **hereditary disorder**?
 No Yes → please specify _____

2.3 Prostate Cancer History

Have you had any of the following screenings:

- a. **digital rectal exam?** No Yes → age of first? _____
 on a regular basis? No Yes → How often? _____
- b. **blood test for prostate cancer (PSA-prostate specific antigen)?** No Yes → age of first? _____
 on a regular basis? No Yes → How often? _____

Have you ever had:

- a. **an enlarged prostate?** No Yes; Date: _____
 if yes, did you have surgery? No Yes Date: _____
- b. **a positive PSA level?** No Yes; Date: _____

2.4 Other Medical Conditions

Have you been diagnosed with any of the following conditions? (Please select all that apply)

- | | |
|---|--|
| <input type="checkbox"/> anemia (chronic) | <input type="checkbox"/> Crohn's disease |
| <input type="checkbox"/> diabetes | <input type="checkbox"/> ulcerative colitis |
| <input type="checkbox"/> hypertension (high blood pressure) | <input type="checkbox"/> obesity |
| <input type="checkbox"/> sleep problems | <input type="checkbox"/> alcoholism |
| <input type="checkbox"/> heartburn (GERD) | <input type="checkbox"/> psychiatric problem |
| <input type="checkbox"/> glaucoma | <input type="checkbox"/> Other: _____ |

2.5 Physical Activity

a.	None	Very light	Light	Moderate	Somewhat hard	Hard	Very hard
Childhood	<input type="checkbox"/>						
High school	<input type="checkbox"/>						
19-29	<input type="checkbox"/>						
30-39	<input type="checkbox"/>						
40-49	<input type="checkbox"/>						
50-59	<input type="checkbox"/>						
60-69	<input type="checkbox"/>						
70-79	<input type="checkbox"/>						

- b. Currently how frequently do you exercise? _____
- c. How much of your work involves physical activity?
 None A little Some Most Nearly all All
- d. How much of your daily routine involves physical activity?
 None A little Some Most Nearly all All

SECTION 3: SOCIAL HISTORY

3.1: Highest level of education Elementary School Middle School High School GED
 Technical/Vocational Certificate Degree College/Postgraduate

3.2: Income and Employment:

a. Income during:	Childhood	Now	b. Current Employment Status
None	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Full time
Up to 4,999	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Part time
5,000-14,999	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Unemployed
15,000-29,999	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Retired
30,000-49,000	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Self-employed
50,000-59,000	<input type="checkbox"/>	<input type="checkbox"/>	
60,000-69,000	<input type="checkbox"/>	<input type="checkbox"/>	
70,000-79,000	<input type="checkbox"/>	<input type="checkbox"/>	
80,000 and above	<input type="checkbox"/>	<input type="checkbox"/>	

c. Employment History

Date Range	Type of work or title	# of years	Exposure to any of the following? (check all that apply)				
			Asbestos	Paints/Solvents	Benzene	Engine exhaust	Lead
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

d. Do you receive government assistance? Yes No Decline to answer

e. Total hours worked each day: _____

3.3. Housing Type:

- a. Homeowner Rent b. Home Apartment Condominium Mobile Home
 c. I live: alone with family with friends d. How many people live in your household? _____

3.4. Neighborhood:

- a. I feel that my neighborhood is safe. Yes No
 b. I know where the parks are in my neighborhood. Yes No
 c. I use the parks in my neighborhood. Yes No
 d. I know the recreational organizations in my neighborhood. Yes No
 e. My neighborhood has places where I can walk. Yes No
 f. I walk or run there Daily 4 Times/week Twice/week Weekly
 Twice a month Less than twice a month Never

3.5. Please rate how much you agree with the following statements regarding your neighborhood?

1= Strongly Agree 2= Agree 3= Neutral 4= Disagree 5= Strongly Disagree

- a. Most people in my neighborhood can be trusted. _____
 b. In my neighborhood you have to be alert or someone is likely to take advantage of you. _____
 c. Most people in my neighborhood are willing to help if needed. _____
 d. In my neighborhood people generally do not trust each other in matters of lending or borrowing money. _____

3.6. Transportation:

- a. I have a vehicle. Yes No
 b. If no, I travel by: taxi bus friend/neighbor family member
 c. I have to travel _____ miles to buy food.
 d. I have to travel _____ miles to see my doctor.
 e. When I go out I mostly go with: (check only one)
 Family Friends Neighbors Co-workers Self Other _____

SECTION 4: PSYCHOSOCIAL HISTORY**4.1. Childhood:**

a. I grew up in the same household with: (Please check all that apply.)

- My mother Grandparent(s) Cousin(s) Sibling(s)
 My father Aunt/Uncle Adopted Other;

b. As a child I lived in: a big city a small city a small town a suburb a rural area a farm

c. For Mississippi Participants:

MS As a child I lived in: The Delta area Northeast MS Central
 Southern MS Coastal MS Southwest
 Other: _____

d. For Nebraska Participants:

Midtown As a child I lived in: North Omaha South Omaha
 West Omaha Other: _____

e. Please indicate the places you have lived (all participants)

Dates or Ages	Place (City, State)	# of Years	Exposure to any of the following? (check all that apply)					
			Asbestos	Paints/Solvents	Benzene	Engine exhaust	Lead	Contaminated Water
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

f. As a child we attended religious services: regularly occasionally on holidays never

4.2. Communication, Trust and Attitudes towards Self

a. Do you have anyone you discuss your health concerns with? No Yes

b. If yes, please indicate who. (Please check as many as apply.)

- | | | | |
|----------------------------------|-------------------------------------|------------------------------------|------------------------------------|
| <input type="checkbox"/> Father | <input type="checkbox"/> Sibling(s) | <input type="checkbox"/> Friend | <input type="checkbox"/> Doctor |
| <input type="checkbox"/> Mother | <input type="checkbox"/> Children | <input type="checkbox"/> Cousin | <input type="checkbox"/> Counselor |
| <input type="checkbox"/> Wife | <input type="checkbox"/> Uncle | <input type="checkbox"/> Co-Worker | <input type="checkbox"/> Other, |
| <hr/> | | <hr/> | |
| <input type="checkbox"/> Husband | <input type="checkbox"/> Aunt | <input type="checkbox"/> Pastor | |

b. To what extent do you trust the following groups of people?

	Extremely	Quite a bit	Moderately	A little bit	None
i. People from your race/ethnic group	<input type="checkbox"/>				
ii. People from other race/ethnic groups	<input type="checkbox"/>				
iii. Local government officials	<input type="checkbox"/>				
iv. State government officials	<input type="checkbox"/>				
v. Federal government officials	<input type="checkbox"/>				
vi. Police	<input type="checkbox"/>				
vii. Your health care provider	<input type="checkbox"/>				

c. How much do you agree with the following statements with regard to your attitudes towards yourself?

1= Strongly Agree 2= Agree 3= Neutral 4= Disagree 5= Strongly Disagree

- i. I am embarrassed to go see the doctor. _____
ii. I feel I am treated with care and respect by my health care provider(s) _____

d. How often do you feel the following:

	Always	Often	Rarely	Never
i. stressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ii. misunderstood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
iii. not listened to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 5: ENVIRONMENTAL HISTORY

5.1. Environmental

a. Have you used any form of tobacco regularly?

- No
 Yes → what type(s)? cigarettes → number of packs per day? _____
 pipe
 cigars
 chewing tobacco
 snuff

b. at what age did you start? _____

c. at what age did you stop? _____

d. total numbers of years smoked? _____

e. lived in the same house with a smoker (if a nonsmoker)? No

Yes → # of years? _____

5.2. a. Have you ever consumed alcoholic drinks?

- No
 Yes → how many per week? 0-3 4-9 10+
what type(s)? _____

b. at what age did you start? _____

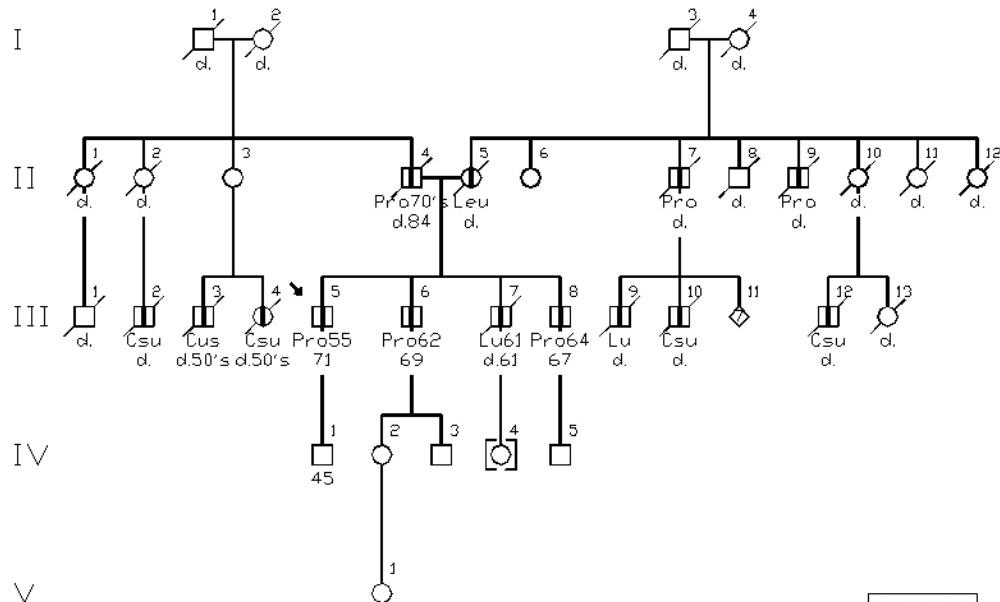
c. at what age did you stop? _____

d. total numbers of years? _____

THANK YOU FOR YOUR TIME AND CONTRIBUTION!

Time Ended: _____ Interviewer Initials: _____

Family A



LEGEND

Male	Female	Description
□	○	Individual number
28	33	Unaffected
33		Current age
■	●	Cancer by Pathology,
Lu53 55	Br45 47	age at diagnosis
		Current age
□/□	○/○	Cancer by Family History,
d.54	d.86	age at death
■	●	Multiple Primary Cancers Unverified
■	●	Multiple Primary Cancers by Medical Records or Death Certificates
★	★	Multiple Primary Cancers by Pathology
■+	+	Cancer by Death Certificate or Medical Records
4		Number of Unaffected Progeny (Both Sexes)
✗		Probond

Pedigree Abbreviations	
Csu	Cancer site unknown
Leu	Leukemia
Lu	Lung
Pro	Prostate

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 402-290-2942

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